

**Julianne Beckett: National Policy Director, Family Voices**

**Testimony Presented to the Health Subcommittee**

**U.S. House of Representatives Energy and Commerce Committee**

**January 16, 2008**

Mr. Chairman and Members of the Committee:

My name is Julie Beckett and I am the Policy Director for Family Voices, a national grassroots organization of families and friends speaking on behalf of children with special health care needs and their families. These families include a number of individuals who are transitioning to the adult system of care and who are anxiously awaiting a life filled with work and play and active participation in their communities. You see when given the types of services needed many of these children and youth can live long and prosperous lives. But access to important programs such as the Early Periodic, Screening, Diagnosis, and Treatment (EPSDT) and special education are critical especially at an early age. Life and death decisions depend on access to the necessary services required by this very vulnerable population.

EPSDT provides the best benefit package for our children and youth with special health care needs. Frequently, it is necessary to access Medicaid even if a child or youth has access to private health insurance. Private insurance is increasingly unwilling to provide access to the types of care that these children and youth need. It is only the protection of EPSDT and the mandate to cover all medically necessary services that guarantees our children access to these necessary services. The federal Medicaid program has taken steps to limit access to this vulnerable population by proposing dangerous

regulations that could limit the important therapies needed to sustain mobility and important physical, mental and life sustaining therapies that allow these children and youth to grow in their communities and participate actively. These therapies and treatments offer the hope of a better future. It also allows children and youth with special health care need and their families to participate more fully in the life of their communities. These services allow us all to experience children and youth with special health care needs and all they are capable of; so that we as a society define them not by their limitations but by their capacity for success despite their mental and physical limitations. (story)

The Maternal and Child Health (MCH) Bureau has just released the latest statistics from the National Child Health Survey which is a random telephone interview with households across the United States. This survey demonstrates that increasingly these children rely on public health insurance because there has been no public outcry in response to the denial of medically necessary services. There also has been no law passed that mandates that when a physician orders treatment or services that are medically necessary, that those services should be paid for by private insurance.

The MCH Bureau's goal to achieve a medical home for every child has eased some of this concern as it cuts down on emergency room care because they have now have a consistent source of care and the services are better organized. In fact, the Medicaid Commission that I was honored to serve on made a recommendation that all individuals covered by Medicaid receive their care from a regular source of care as used in the Maternal and Child Health Bureau Medical home model.

This goal of achieving a medical home for every child must not be attached to complicated payment structures like those used in managed care. Payment incentives can have a negative impact and can limit care that should be provided. (STORY-ED) Again, this demonstrates, as shown in the MCH Bureau's National Survey: Children and youth do best when they are part of a medical home and the cost of care either stays the same or decreases as families are financially able to provide for the extensive care needs of their child or youth.

This too can apply to adult care when targeted case management helps access the right kinds of services necessary for an individual to stay in their communities and actively participate in work. (story) The Family Opportunity Act that was built on the Ticket to Work and Work Incentives legislation provides for families and individuals with disabilities to access a Medicaid buy-in program so that these families and individuals are "employable" when a company does not have to use all of their health benefits to pay for services that these workers may need. I am proud of the fact that my daughter Katie served on the Advisory panel for several years and actively participated in the beneficiary summit that identified the barriers young people with disabilities face when forced to remain on Social Security programs that present barriers to their work participation. The Medicaid buy-in programs give them hope that someday they may not have to rely on these outdated programs that restrict what individuals can do.

The Community Care Act approaches many of these concerns but families need options. Improvements in Medicaid delivery certainly would provide them with some choice in helping their children and young adults survive and prosper. It is agreed that it would be much more beneficial to efficiently and effectively manage a benefits program

that helps our children and youth survive rather than relying solely on a cash payment subsidy and restrictions that limit their options. I hope that you will look long and hard at the final report of the Ticket to Work and Work Incentives Advisory Panel even though this committee does not have jurisdiction and think about the decisions you make that could impact its success.

Finally, removing targeted case management from the list of options makes no sense. Nor does restricting school based incentives that help special education students achieve in schools. And of course it makes no sense to limit reimbursement for therapies that keep their bodies moving in a direction that keeps them able. Again EPSDT provides for the most essential medically necessary services-no matter where those services are provided. Limiting the nature of this program to simply “cure” would certainly fly in the face of Congressional intent. I would hope that this committee would examine your options to learn more about what these initiatives do and the impact of the current proposals on real lives and real families.